

**GZJ KDK"! 2'"'**



*American Pain Foundation*

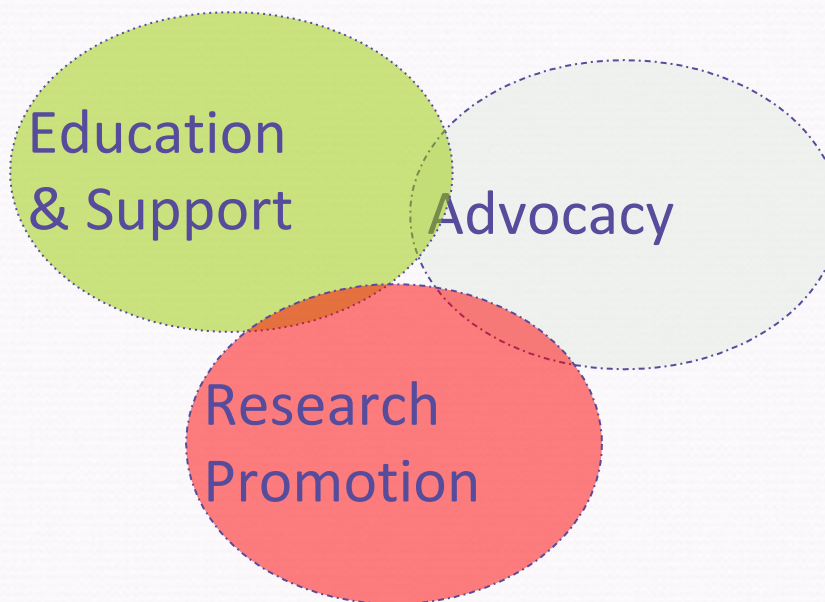
A United Voice of Hope and Power over Pain

# **American Pain Foundation Today and Tomorrow**

## **November 2011**

# About APF

An independent, nonprofit organization serving **people with pain** through information, advocacy and support



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# Vision and Mission

**Vision:** To eliminate pain as a major public health problem.

**Mission:** To educate, support and advocate for people affected by pain.

**Strategic Vision:** APF is 2 million supported and supportive members.



# Advocacy

- **Pain Care Forum:** Principal organizer and leader of 62 member organization coalition committed to improving federal pain policy
- **American Pain Foundation Action Network:** National Advocacy Network of educated and trained advocates
- **Washington State Advocacy Focus**
- **Principal organization in the newly formed State Pain Policy Action Coalition**
- **“The Pain Project”:** To be launched in 2012. A viral strategy for building a pain movement, gathering vital data, targeting advocacy and educational actions





# Pain Care Forum

- 62 Member organizations representing patients, nurses, pharmacists, doctors, hospice, abuse community, pain education, medical ethics, and pain policy
- Task Forces: a) REMS, B) Acetaminophen, C) Legislative, D) IOM Task Force
  - Each with Action Sub-committees
- **REMS Task Force: 35 organizations:**
  - Created coordinated messaging to the FDA
  - Active presence at public meetings
  - Over 2,500 responses to the FDA Docket
    - APF Public Petition had over **4,000 submissions**
  - 4 sub-committees---Legislative, Congressional Strategy, Messaging, and Data Points





# Pain Care Forum

- **Acetaminophen Task Force:** 16 organizations:
  - Produced and disseminated messages regarding the FDA Advisory Committee acetaminophen recommendations
  - Generated over 250 responses to the FDA Docket
  - APF Public Petition:  
(<http://www.thepetitionsite.com/petition/362024837>)
    - Generated over **3,200 submissions** in 3 weeks
  - 3 subcommittees---Scientific Meeting, Icon, and Education
    - Ongoing education and strategizing



# Legislative Strategy Committee

- Successfully passed the Veteran's Pain Bill in 2008; the Military Pain Bill in 2009; and the provisions of the National Pain Care Policy Act in 2010
- The Veteran and Military Pain Bills require VA and DOD require each to develop comprehensive pain treatment plans to be implemented and progress reported to Congress annually
- The NPCPA provisions include: a) IOM Conference and Report; b) NIH Research Plan and Interagency Advisory Committee; c) HRSA Training and Education Grants Program



# IOM Task Force

## Task Force Actions:

- Distributed information about IOM Report to 800+ organizations
- Engaged and continues to work with the CDC to implement CDC recommendations in IOM Report
- Commitment from Senator Harkin to hold a HELP Committee Hearing on the IOM Report
- Committed to long-term work to promote implementation of IOM recommendations







# Grassroots In Action

- **APF Action Network:** <http://www.painfoundation.org/take-action/action-network/>
  - Combined force of trained persons living with pain and healthcare professionals
  - Database of over 40,000 available to take action
- **Activities:**
  - Advocacy actions at state and national levels
  - Public awareness activities
  - Focus on activities during Pain Awareness Month (PAM)
- **Action Network Summit**
  - Training and Alliance Building of action leaders **AND** advocates from over 17 national organizations





# Online Advocacy Center

## Targeted Actions For Results

2010 State Alert/Announcement Summary

Total # of Alerts – 75

Focus included:

- Step Therapy & Therapeutic Switching
- Worker's Compensation/Chronic Pain Guidelines
- Washington State Policy issues
- Announcements of Action Network events
- State targeted, for national effort – Shingles vaccine, IOM study involvement, PMDP issues, Pain Mill issues



# Summit 2009



# EDUCATION





# Principal Educational Efforts

- **Website:** Thousands of pages of educational and support information
- **Publications:** *Treatment Options, Exit Wounds, Is Fibro the Cause, Resource Guide, Bill of Rights, Describa Su Dolor*, a dozen other
- *Pain Community News* and *Pain Monitor*
- *PainSAFE*
- *NIPC*
- *Med Ed*
- *Community Events*
- *Pain Awareness Month Activities*





# Educational Initiatives (cont)

- “Spotlights On...” Breakthrough Cancer Pain, on Shingles, Military and Veterans Pain, Back Pain, Pain In Older Adults (2012)



# APF IS THE LEADING GO-TO RESOURCE FOR MEDIA COVERING PAIN



**APF IS REACHING MILLIONS—  
THROUGH PROACTIVE MEDIA OUTREACH AND  
CONTROLLED COMMUNICATION STRATEGIES**

**TOTAL MEDIA IMPRESSIONS IN 2010:**

**405,785,000 +**

145 media placements

**MEDIA IMPRESSIONS FIRST HALF 2011:**

**286 million +**

211 media placements and growing!





*American Pain Foundation*

A United Voice of Hope and Power over Pain

# ***The Pain Project***

## ***2012 to 2016***

Concept Overview



# 2012 to 2016

## STRATEGIC OBJECTIVES

- APF conducted an intense Strategic Planning Process in 2010 and articulated a focus on CAPACITY
- “Capacity” means: 2 million satisfied and engaged members
- 2 million members means:
  - Significantly greater ability to help people in pain
  - Significantly greater advocacy strength
  - Significantly greater and more diversified funding



# What Will It Take?

- A smart, scalable and cutting-edge campaign that engages large numbers and speaks directly to the population of people with pain and the public that....
  - Goes OUTSIDE THE BOX
  - Allows their voice to be heard
  - Visibly shows the state of pain care in America
  - Is highly scalable
  - Creates a simple and dynamic resource/support locator (e.g., local support groups)



# So What is “It?”

*The Pain Project*

[www.painproject.org](http://www.painproject.org)

*Powered by the APF*





# Core Elements

1. Dynamic “state of care map:” Interactive blog + mapping software interface allowing anyone to report on barriers that impede access and visibly displays state by state crisis facing PWPs
2. Dynamic “support map:” Interactive blog, combined with social media (FB, Twitter, Meetups) establishing an interactive portal to connect with local supports
3. Linkage to APF Educational and Support Services utilizing newly established APF Constituent Management Capacity
4. Action oriented engagement: blogs, petitions, story telling, issue advocacy
5. Full engagement of APF Action Network at local levels





HOME

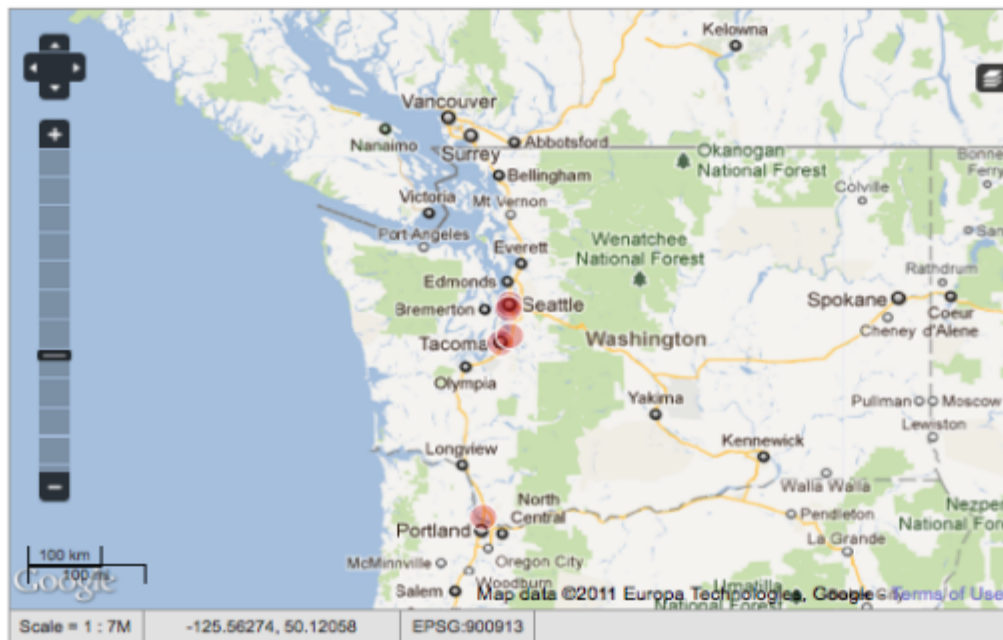
REPORTS

SUBMIT A REPORT

CONTACT US

FILTERS → **REPORTS** NEWS PICTURES VIDEO ALL

+ CATEGORY FILTER [HIDE]

From: **Aug 2011** to: **Sep 2011**

PLAY

**ALL CATEGORIES**

ED - NO OPIOID

NO OPIOID THERAPY

NO PAIN CARE

NO MEDICAID

**How to Report**

1. By filling this form

**RSS Feeds (copy the url below)**
<https://stateofcare.crowdmap.com/feed/>
**Reports (from the map, listed in chronological order)**

TITLE	LOCATION	DATE
UW Neighborhood Federal Way Clinic	Federal Way,	Sep 15

**Official & mainstream news**

TITLE	SOURCE	DATE
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# Benefits

- A major engagement mechanism to attract and retain members
- A major resource for issue data including numbers, types of issues, potential advocates and spokespersons
- A major capacity to “get personal and local”
- A major resource for advocacy planning and actions
- Visible place to show the specific policy initiatives of the SPPAC
- Portal to connect each Action Network leader to potential “troops” in their states



# Cutting Through the “Noise”

The screenshot shows the 350.org website homepage. At the top, there is a navigation bar with language options (English, Français, Español, Deutsch, Português) and regional links (Africa, Australia, Brasil, Mexico, New Zealand). The main header features the 350.org logo, a "What is 350?" button, and a menu with links to ABOUT, RESOURCES, MEDIA, CAMPAIGNS & PROJECTS, SIGN UP, and DONATE. The central banner reads "WE'RE BUILDING A GLOBAL MOVEMENT TO SOLVE THE CLIMATE CRISIS." and includes a "JOIN IN:" field with a placeholder "YOUR NAME". To the right of the banner, text states: "Our online campaigns, grassroots organizing, and mass public actions are led from the bottom up by people in 188 countries. [Read more...](#)" Below this, social media follow buttons are shown: "Follow @350 - 72.9K followers" and "Like 173k". The lower section contains three main promotional tiles: 1) "#OCCUPY AND THE CLIMATE MOVEMENT" with a "JOIN THE 99%" button; 2) "WATCH THE MOVING PLANET WRAP-UP VIDEO!" with a video thumbnail; 3) "NOV 6TH" campaign titled "Encircle the White House to stop the Keystone XL Pipeline." with a "GET INVOLVED" button. A "MORE PROJECTS" sidebar lists: "Climate Leadership Workshops", "The U.S. Chamber of Commerce Doesn't Speak For Me!", "Which Side Are You On? - A campaign to take on dirty money in US politics. [BETA]", "Powershift Conferences", and "eARTh: Climate Art Projects". At the bottom, there is a "350 Updates" section with a post from 11/04/11 titled "Speaking Slowly in Saigon" and a "The Science of 350" section featuring a "CO2" graphic and text: "Scientists say that 350 parts per million CO2 in". A small profile card for Kelly Blynn with a "Share this" button is also visible.



# Outcomes

- A large-scale MOVEMENT to change pain care and policy
- Stakeholder engagement in a way we never have before  
= an engine for rapid and sustained membership growth
- Leveraging of grassroots, bottom up energy to build the movement, through FB, Twitter, Meetups, etc.
- Integration of core capacities of the APF (e.g., Action Network, CMS, Education and Support Services)
- A public “Storefront” for PWPs to be heard and find support



# DISCUSSION



THANK YOU!

